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Psychological Acceptance and Family Quality of Life in Families of
Children with Intellectual Disabilities

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I dedicate this thesis to my daughter Charlotte, you are my world. You have given me true insight into the joys (and challenges!!) of being a parent

xxx

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Thesis Abstract

In order to examine the literature on acceptance and mindfulness in parents of children with developmental disabilities a systematic review was conducted. Twelve studies were included in the review and provided some support for the relevance of these concepts in helping to support parents of children with developmental disabilities. However, general study quality was poor and methodological limitations hampered confidence in these findings. Research considerations are discussed. An empirical study was conducted to examine the relationship between psychological acceptance and family quality of life in parents of children with intellectual disabilities. One-hundred and twenty-nine parents of children with intellectual disabilities participated in a questionnaire based study. Participants completed measures of family quality of life, psychological acceptance, emotional adjustment, mental well-being and impact of the child. Parental psychological acceptance was positively associated with family quality of life and was found to account for around 1.9 per cent of its variance. Parental emotional adjustment was also positively associated with family quality of life, however, when parental psychological acceptance was added to the regression model emotional adjustment was no longer a statistically significant variable. The results of this study suggest that parental psychological acceptance may explain some of the variance in family quality of life. Further research is needed to ascertain whether interventions that improve parents' psychological acceptance also improve family quality of life.

Systematic Review

Acceptance and mindfulness in parents of children with developmental disabilities – a systematic review of the literature.

Allison Walsh, David Gillanders & Renate Kuenssberg

Produced in accordance with style guidelines for the Journal of Applied Research in Intellectual disabilities

Abstract

Background Acceptance and mindfulness interventions have been shown to be useful for a variety of psychological conditions including depression, stress and chronic pain. Recent research in the developmental disabilities field has focused on the psychological factors that affect the well-being of parents of children with developmental disabilities

Method A systematic review was conducted to explore the literature on acceptance and mindfulness in parents of children with developmental disabilities. Searches of electronic databases CINAL, MEDLINE, PsychINFO, Psychology and Behavioural Sciences and Web of Science were conducted. Experts in the field were also contacted to ascertain whether any 'In Press' articles met inclusion criteria for the review.

Results Twelve articles met the inclusion criteria for the review. Six of the studies employed a cross sectional design with the remaining six being intervention studies. The cross sectional studies appear to indicate that parental acceptance and mindfulness is associated with greater parental well-being. However, due to the methodological limitations of the studies reviewed, confidence in this finding is limited. The intervention studies reviewed also indicated that acceptance and mindfulness interventions may be beneficial in helping to support parents of children with developmental disabilities. Again however, methodological limitations hamper our confidence in this finding.

Conclusion The evidence reviewed provides some support for the usefulness of acceptance and mindfulness concepts and interventions in helping parents of

children with developmental disabilities. Poor study quality and methodological limitation limit confidence in this finding. Future research considerations are discussed.

Introduction

For many people becoming a parent is often a time of happiness and expectation. From the time of conception (and even before) many parents have ideas, beliefs and expectations about their child and the person they will become in the future. Although parenting brings many rewards it can often be challenging, especially for parents of children with developmental disabilities. These parents often have to manage multiple demands including additional medical appointments, accessing specialist services, understanding complex information and fighting for scarce resources (Glidden *et al.* 2006; Lloyd & Hastings 2009). As well as dealing with the additional practical burdens, parents of children with developmental disabilities also have to emotionally adjust to their child's condition and limitations.

Research suggests that parents of children with developmental disabilities experience more distress and have an increased risk of developing mental health problems than parents of typically developing children. (Hastings 2007; Lloyd & Hastings 2008; Olsson & Hwang 2002; Singer 2006) Parents of children with developmental disabilities can feel responsible, blamed, guilty and ashamed of their child's condition (Blackledge & Hayes 2006). It is therefore not surprising that these parents experience higher levels of depression and anxiety and many researchers feel that this is as a result of the additional stress and adjustments these parents have to make due to having a child with a developmental disability. However, not all parents of children with developmental disabilities report significant difficulty, indeed for

many parents bringing up a child with developmental disabilities has many rewards including increased patience and empathy and improved relationships with others (Turnbull *et al.* 1993; Benson 2010).

Parental adjustment is a complex process which involves many elements including child, family, environmental and psychological variables. Recently there have been a number of studies which have found that psychological processes such as parental self efficacy, locus of control, self-esteem, and acceptance can have an effect on parental wellbeing (Hastings & Brown 2002; Lloyd & Hastings 2009; McDonald *et al.* 2010).

Acceptance and mindfulness are closely linked concepts and are two psychological processes that may have an impact on parental well-being, parent/child relationships and family functioning.

Acceptance

Psychological acceptance can be defined as *“the voluntary adoption of an intentionally open, receptive, flexible, and non judgemental posture with respect to moment to moment experience”* (Hayes *et al.* 2012, p.272). Within the context of parents of children with intellectual disabilities and Autism Spectrum Disorders (ASD) this seems to be a useful concept as often the thoughts and feelings experienced by these parents are not inaccurate, distorted or exaggerated given the real challenges they face. Acceptance approaches are an alternative to traditional cognitive behavioural approaches as rather than attempting to alter cognitions they aim to encourage parents to accept these uncomfortable thoughts and emotions and maintain contact with

the present moment. This seems particularly applicable to parents of children with developmental disabilities and it has been suggested that “being able to accept the challenges that one is unable to change may be as helpful or more helpful than advocating for services” (Weiss *et al.* 2012).

Mindfulness

Mindfulness and its features can be conceptualised in many ways and this is borne out by the variety of definitions that are displayed in the relevant literature (Ferraioli & Harris 2012). The underlying principal of mindfulness is the non-judgemental awareness of moment to moment experience. Harnett and Dawe (2012) describe mindfulness as *“a process of developing a non-judgemental accepting awareness of moment-by-moment experience.....(which) involves intentionally attending to one’s ongoing stream of sensations, thoughts and emotions as they arise, without evaluating these phenomena as good or bad”* p1. Kabat-Zinn and Zabat-Zinn (1997) describe mindful parenting as involving continually paying attention in a deliberate and non-judgemental way to one’s child and parenting.

Acceptance and mindfulness are concepts that are brought together in the practice of Acceptance and Commitment Therapy (ACT, said as one word, not three letters). ACT aims to encourage an individual to accept things that are not within their personal control and to commit to action which enhances and enriches their lives. ACT uses mindfulness techniques to teach participants the psychological skills required to manage painful thoughts and feelings effectively so that when they occur they are unhooked from

behavioural responding. ACT also aims to help individuals identify what is truly important in their lives and to encourage and support change so that these goals and values can be achieved. (Harris 2006). ACT has been shown to be useful for a variety of psychological conditions including depression, stress and chronic pain (Bond & Bunce 2000; Dahl *et al.* 2004; Ruiz 2010). Given the success of ACT in a variety of conditions and the developing literature on acceptance and mindfulness research in parents of children with developmental disabilities this review will examine the literature available on acceptance and mindfulness in parents of children with developmental disabilities. It will attempt to investigate the following questions:

1. Is there a relationship between psychological acceptance and well-being in parents of children with developmental disabilities?
2. Is there a relationship between mindfulness and well-being in parents of children with developmental disabilities?
3. Are acceptance and mindfulness based interventions effective at improving the well-being of parents of children with developmental disabilities?

Method

Search strategy

Search results were limited to English language only due to cost and practicalities of translation of texts. Only articles published or accepted for publication in peer reviewed journals were included.

A literature search using the following databases was carried out in January 2014; CINAHL (1980 until present); MEDLINE (1980 until present); PsychINFO (1980 until present); Psychology and Behavioural Sciences Collection (1980 until present) and Web of Science (1980 until present). The following search terminology was used (psychological accept* OR mindful* OR psychological flex* OR contextual behav*) AND (intellectual dis* OR learning dis* OR mental ret* or Autis*) AND (parent* OR famil* OR mother* OR father*). A search using the internet search engine 'Google' was also conducted. Reference lists from articles were examined and prominent authors in the field were contacted to ascertain whether there were any articles 'In Press' that could be used.

Inclusion and exclusion criteria

Articles that looked at either acceptance or mindfulness in parents of children with developmental disabilities were included. For the purpose of this systematic review the term developmental disabilities included children who the authors reported to have either an intellectual disability, an Autism Spectrum Disorder, Mental retardation or a Learning Disability (as defined by British terminology). Two articles were excluded after being read in full as the

term “learning disability’ used was based upon the American definition and therefore did not meet inclusion criteria. No articles were excluded based upon study quality.

Critical Appraisal

The quality of the studies was assessed using a pro-forma designed by the author which was based on quality appraisal checklists recommended by the National Institute of Clinical Excellence (NICE) and the Scottish Intercollegiate Guidance Network (SIGN). Each paper was reviewed using the following quality criteria; representativeness of source population or area; selection of participants representative of eligible population; control or comparison group; sound theoretical basis, confounding factors identified and controlled for; use of a valid and reliable outcome measures, sample size and power; appropriate statistical analyses; internal validity and external validity. Each item was scored either 0,1 or 2 depending upon how well the study fulfilled the individual criteria with overall maximum score being 20.

Results

The search strategy identified 194 articles. The author read through the article titles/abstracts to identify any article that met the inclusion criteria. After removing duplicates and reading relevant full texts, ten publications met inclusion criteria. The author then contacted prominent researchers in the field via email. Four researchers responded which yielded one paper that also met the inclusion criteria. Reading of the reference lists and using an internet search did not identify any additional papers that were relevant for this systematic review.

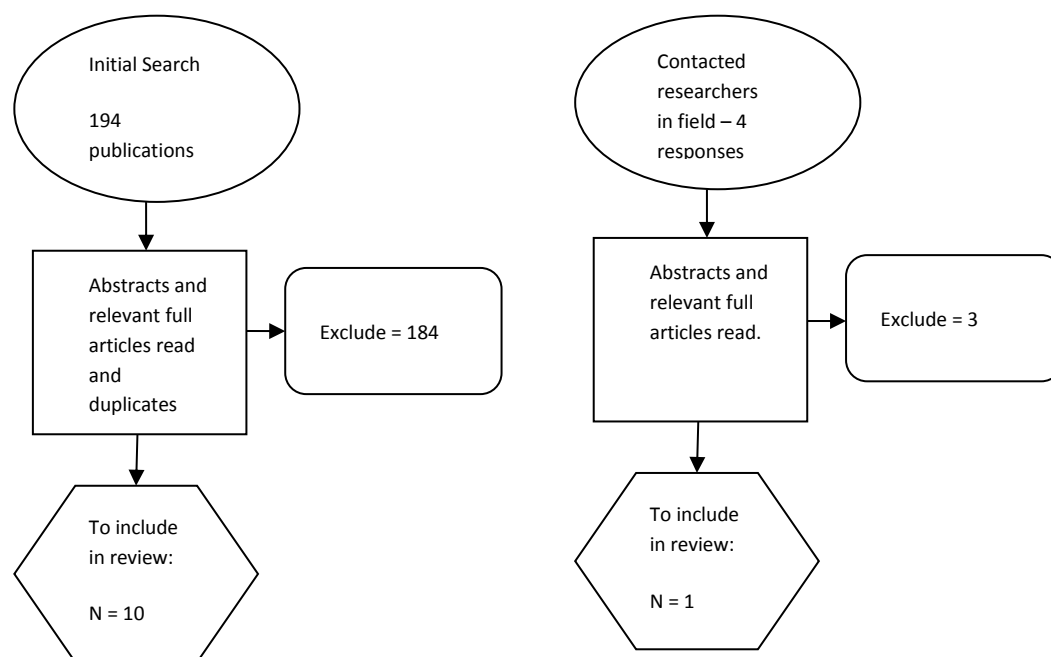


Figure1. Flow chart to depict the search process

Overview of studies reviewed

A summary of the studies characteristics and findings is displayed in Table 1. Five of the studies employed a cross-sectional design with the remaining six being intervention based, within subjects design. Five of the studies were

conducted in the United States of America, three in the United Kingdom, two in Canada and one in Australia. The sample sizes ranged from 3-228. The ages of the children ranged from 1-21 years.

Table 1- Study Characteristics and Brief summary of Findings

| <u>Authors</u> | <u>Year</u> | <u>N</u> | <u>Country</u> | <u>Study Design</u> | <u>Age</u> | <u>Summary of Main Findings</u> |
|-----------------------|--------------------|-----------------|-----------------------|---|-------------------|--|
| Neece | 2013 | 46 | America | Within subjects/Between subjects design | 2.5-5 | Parents who participated in Mindfulness based stress reduction reported significantly less stress and depression and increased life satisfaction than those who did not participate in the intervention. |
| McDonald et al | 2010 | 99 | Ireland | Cross sectional | 6-18 | Psychological acceptance partially mediated the impact of child behavioural problems on fathers' mental health. |
| Beer et al | 2013 | 28 | Australia | Cross sectional | 1-17 | Higher levels of mindful parenting were related to lower levels of depressive symptoms and stress. Higher levels of behaviour problems associated with more parental mental health difficulties and lower levels of mindful parenting. Mindful parenting may be beneficial for parental mental health. |
| Jones et al | In Press | 110 | Wales | Cross sectional | 7-16 | Psychological acceptance and mindfulness have significant mediation effects for maternal anxiety, depression and stress. |
| Blackledge & Hayes | 2006 | 20 | America | Within subjects , repeated measures | Not available | Following participation in acceptance and commitment therapy (ACT) group participants scores on measures of depression and psychological distress improved following intervention. |
| Singh et al | 2006 | 4 | America | Within subjects repeated measures | 2-6 | Following mindfulness training mothers reported lower parenting stress, greater satisfaction with their parenting, more social interactions with their child and greater practice of mindfulness. |

| | | | | | | |
|--------------------|------|-----|-----------|--------------------------------------|---------------|---|
| Lloyd & Hastings | 2008 | 91 | England | Cross sectional and Longitudinal | | Mothers who were more psychologically accepting reported fewer psychological adjustment problems. Longitudinal analysis showed that acceptance is bidirectionally related to anxiety and depression. |
| Weiss et al | 2012 | 228 | Canada | Cross sectional | 6-21 | Psychological acceptance and empowerment were negatively associated with parental mental health difficulties. Only acceptance was a significant mediator between child problem behaviour and parental mental health difficulties. |
| Ferraioli & harris | 2012 | 15 | America | Between subjects and within subjects | Not available | The mindfulness group demonstrated statistically significant improvements on parental stress and global health outcome measures. |
| Singh et al | 2006 | 3 | Not Known | Within subjects | 4-6 | After participation in a 12-week course, mothers who were more mindful in their parenting had children who displayed less aggression, were more compliant and showed less self injurious behaviour. Mothers' satisfaction with their parenting skills also increased. |
| Weiss et al | 2012 | 35 | Not Known | Within Subjects design | 8-14 | After participation in the group results indicate increases in parent service empowerment and psychological acceptance. |

Table 2. Quality Appraisal Scores

| Criteria | Neece (2013) | McDonald et al (2010) | Beer et al (2013) | Jones et al (In Press) | Blackledge & Hayes (2006) | Singh et al (2006) | Lloyd & Hastings (2008) | Weiss et al (2012) | Ferraioli & Harris (2012) | Singh et al (2006) | Weiss et al (2012) |
|---|--------------|-----------------------|-------------------|------------------------|---------------------------|--------------------|-------------------------|--------------------|---------------------------|--------------------|--------------------|
| 1. Is the eligible population representative of the source area? | 1 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 0 | 0 | 1 |
| 2. Do the selected participants or areas represent the eligible population or area? | 1 | 0 | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 0 | 1 |
| 3. Was there a control/comparison group? | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 |
| 4. Was the selection of explanatory variables based on a sound theoretical basis? | 2 | 2 | 2 | 2 | 1 | 2 | 2 | 2 | 1 | 1 | 1 |
| 5. How well were confounding factors controlled for? | 1 | 1 | 0 | 1 | 0 | 0 | 2 | 2 | 0 | 0 | 0 |
| 6. Were the outcome measures and procedures reliable? | 1 | 1 | 1 | 2 | 1 | 0 | 2 | 2 | 0 | 0 | 1 |
| 7. Was sample size and power adequate? | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 8. Was appropriate analysis of outcome measures used | 2 | 2 | 2 | 2 | 1 | 0 | 2 | 2 | 1 | 0 | 1 |
| 9. Are the study results internally valid? | 1 | 1 | 0 | 1 | 0 | 0 | 1 | 1 | 0 | 0 | 0 |
| 10. Are the study results externally valid? | 1 | 1 | 1 | 1 | 0 | 0 | 1 | 1 | 0 | 0 | 1 |
| Total Score | 11 | 9 | 7 | 10 | 4 | 2 | 12 | 12 | 3 | 1 | 6 |

Critical Appraisal of Study Quality

The studies will now be grouped by their design (cross-sectional or intervention) and critically appraised. The overall quality of the studies was poor (see table 2 for the quality appraisal scores of all twelve studies). The second author graded six of the papers and there was perfect agreement in 85% of the ratings. The minor discrepancies in grading were discussed and resolved. None of the differences were more than one point apart.

Cross-sectional Studies

MacDonald et al (2010) examined the relationship between psychological acceptance of negative thoughts and emotions regarding having a child with an intellectual disability, child behavioural problems and paternal mental health. They found that psychological acceptance partially mediates the impact of child behavioural problems on paternal mental health. They also found that fathers who were more psychologically accepting perceived greater positive gains associated with raising a child with intellectual disabilities. Limitations of the study are that the sample was potentially not representative and no power calculations being reported. The authors controlled for relevant demographic variable but there were other potential confounding factors that were not considered e.g. mothers role in child care, social support received from extended family.

The majority of the measures used in this study were well established and had adequate scores of validity and reliability. However, the measure of psychological acceptance was unique to this study therefore there was limited information available regarding its psychometric properties. Initial data were encouraging however and it has subsequently been used in a number of following studies and has been shown to be adequate. The study again depended upon father's self report on all measures and, as the authors themselves acknowledge this may have resulted in reporting biases. As the study was cross sectional in design no claims of causality can be made.

Beer et al (2013) conducted a study looking at mindful parenting in parents of children with Autism Spectrum Disorder (ASD). They asked participants to complete a questionnaire about their child's behaviour problems, parental stress, depressive and anxiety symptoms and mindful parenting. They also asked open ended questions about mindful parenting methods and overall parenting experiences. Their results suggest that higher levels of mindful parenting are related to lower levels of stress and depressive symptoms. They found no relationship between mindful parenting and anxiety symptoms. Higher levels of child behavioural difficulties were related to more severe mental health symptoms and lower levels of mindful parenting. Preliminary analysis suggested that mindful parenting did not mediate the relationship between behavioural problems and parental distress.

The research was of a questionnaire based design and of 173 participants who were invited to participate only 28 responded (16%). This means that the sample of respondents may not be representative of parents of children with ASD and therefore

limits the generalisability of the study results. Also, participants were recruited over a five year time period (January 2005-December 2010) and 28 participants seem a small number given the time frame. As already stated the sample size was small and no power calculation was provided. There was no control group and the authors did not control for, or appear to consider, any potential confounding variables.

The measures used within the study were acceptably valid and reliable and the statistical analyses used appropriate. The study depended upon parental self-report and this may have resulted in reporting biases. As the study was cross sectional in design, no claims of causality can be made.

Jones et al. (In press) explored whether psychological acceptance and mindfulness were mediating factors in the relationship between child behavioural difficulties and parental psychological well-being in parents of children with ASD. Their results suggest that psychological acceptance is a mediator variable for maternal anxiety, depression and stress and for paternal depression. They also found that general mindfulness and mindful parenting were significant mediators for anxiety, depression and stress in mothers.

This study was of questionnaire based design and of the 215 invitations to participate sent 71 families responded (33%). In 39 families both parents participated therefore the total number of participants was 110. This suggests that the sample may not be representative of parents of children with ASD. Although the sample size appears to be adequate no power calculation was reported. The authors controlled for a variety of confounders such as marital status, child gender

and severity of ASD symptoms. The majority of measures used in this research were well established and were of adequate validity and reliability. There was a new mindfulness measure developed for this research which has yet to be established however the reported internal consistency was adequate (Cronbach's α .79 for mothers and .78 for fathers). The authors also suggest that the construct validity of the scale was encouraging with strong correlations between the new measure and The Five Facets Mindfulness Questionnaire (FFMQ; Baer et al 2006) . This study also relied solely upon parental self report which may have resulted in reporting biases. As the study was cross sectional in design no claims of causality can be made.

Weiss et al (2012) conducted a study looking at the impact of child behavioural problems on parental mental health in families of children with ASD, examining the mediating role of psychological acceptance and parental empowerment. Their results suggested that psychological acceptance and empowerment were negatively related to the severity of parental mental health problems, however only psychological acceptance was a significant partial mediator between child problem behaviour and parental mental health. 228 parents participated in the study and they were recruited via advertisements on several Canadian Asperger and Autism advocacy websites. As participants were self selecting it is unclear whether they can be considered to be representative of this population as a whole. The vast majority of participants were female (93%) therefore results may not generalise to fathers of children with autism spectrum disorders. A further limitation with the sample is that parents who did not have access to or use the internet may have been excluded.

The majority of participants identified themselves as European Canadian and highly educated therefore the results may not be generalisable in these respects.

A strength of the study was that the authors identified and controlled for a number of potential confounding factors including child related factors (age, ASD symptoms, gender), socioeconomic status, and negative life events experienced in the last year. The measures used in the study were of acceptable validity and reliability. The sample size appeared large (228) but no power calculation was reported. The authors clearly stated their aims and hypotheses and the statistical analyses used were appropriate and well reported. The study relied upon self report leaving it open to potential reporting biases. It was also cross-sectional by design therefore causal inferences are limited.

Lloyd and Hastings (2008) carried out a questionnaire based study examining whether the psychological variables of acceptance, mindfulness and avoidant coping can explain variations in mothers' psychological well-being. Their results suggested that mothers who were more psychologically accepting reported fewer symptoms of anxiety, depression and stress. Data were gathered from 91 mothers of children with intellectual disabilities who attended special schools in the south-east of England. Of 17 special schools approached only nine chose to participate. There is no information regarding how many mothers in these nine schools were invited to participate therefore it is unclear whether the sample can be considered representative. Of 130 mothers who initially responded to advertisements, 91 returned completed data (70%). The authors identified and controlled for a number of potential confounding factors including family deprivation and child behavioural

problems. All of the measures used within the study were considered to be of acceptable reliability and validity. The sample size appears sufficient however no power calculations were reported. Aims and hypotheses of the study were clearly stated and appropriate statistical analyses were conducted. Again, this study relied upon mother's self report which is liable to reporting biases.

The studies considered above share many methodological issues including that their samples are mainly female, they rely upon self-report, they have low response rates (although typical of this type of study) and are cross sectional in design therefore no causal inferences can be made. The studies considered appear to indicate that parental acceptance and mindfulness is associated with greater well-being, even after controlling for some relevant confounds. However, due to the methodological limitations highlighted above, our confidence in this finding is limited.

Intervention Studies

Neece (2014) conducted a study which looked at the effectiveness of a mindfulness based stress reduction (MBSR) group for parents of children with developmental disabilities. The results suggest that parents who participated in the MBSR group reported significantly less stress and depression than those who were in the control group. It was also reported that parents' life satisfaction was greater and that they reported that their children had fewer behavioural difficulties following participation in the MBSR group.

The eligible population was described well however there were a number of exclusion criteria including parents who were non-English speakers and children who had debilitating physical conditions or severe intellectual disabilities. Ninety-five families were screened for the study but only sixty-three (60%) were deemed to meet the inclusion criteria. Of those 63 eligible, 46 parents made up the final sample. These exclusion criteria and dropout rate mean that the study results may not be generalizable to the source population.

Participants were randomly allocated to either the treatment group or a wait list control group and these groups did not differ significantly on any of the demographic variables. Prior to intervention the groups did not differ significantly on the measures of stress, depression or life satisfaction and therefore they can be considered to be a well matched comparison group. The study used a variety of measures which were generally considered to be acceptable in terms of both reliability and validity. The aims of the study were clearly stated and the statistical analyses used were appropriate and reported well. However, the sample size was small and there was no power calculation reported.

The study did not use an active treatment group therefore the findings only suggest that MBSR is better than no treatment. Another limitation of this study is that all the measures used relied upon parental self report therefore reporting biases may have influenced results.

Blackledge and Hayes (2006) conducted a study looking at the effectiveness of an Acceptance and Commitment Therapy (ACT) group in helping parents of children

with autism better adjust to the difficulties of raising their child. As described by the authors “*ACT emphasizes acceptance of unpleasant emotions, defusion from difficult thoughts, clarification of the client’s personally held values and corresponding goals, and enhancement of the client’s effectiveness in moving towards those values and goals*” (Blackledge & Hayes 2006 p.3). This study used a within-subject, repeated measures design to test the effectiveness of a 14 hour group ACT workshop with 20 parents of children with Autism. The results suggest that general distress and depression levels decreased significantly following participation in the group and that these decreases were maintained at 3 month follow up.

The authors did not provide information about exclusions although they claimed to attempt to reach the ‘normal mainstream’ of parents of children with autism. There was no information supplied regarding how many participants they attempted to recruit therefore it is unclear how well the selected participants represent the eligible population or area. There was no control or comparison group used and authors did not control for confounding factors that may have affected outcome e.g. social support or expectancy of treatment effectiveness. The measures used were generally of acceptable validity and reliability although the reliability of the acceptance measure used (AAQ, Hayes *et al.* 2006) was at the low end of the range considered to be adequate. The sample size was small and no information regarding power was reported. The authors did find statistically significant outcome changes however these were small and may not be clinically relevant (an average change of four points on the depression measure between pre, post and follow up). Half of the recruited participants were couples and there was an assessment non completion rate of 11%.

Ferraioli and Harris (2013) conducted a study evaluating the effectiveness of a mindfulness based parent training approach for parents of children with Autism. Fifteen parents were matched on their scores on the Parental Stress Index – Short Form (PSI-SF) (Abidin 1995) and then randomly allocated to either the Mindfulness-Based parent training group or the Skills-Based parent training group. Parental stress and global health were measured pre-treatment, post-treatment and at 3 month follow up. Results indicated that only the mindfulness group showed significant improvement on both outcome measures following participation in the 8 week program.

Sixty-seven participants were contacted and 31 people responded (46.2%). However, of those who responded 10 were excluded (31%) due to either not meeting the inclusion criteria (2) refusal to participate (6) or other reasons (2). The 21 participants remaining were then randomly assigned to one of the groups. Of the 10 participants in the mindfulness group, only 6 completed the allocated intervention and were used in the analyses (40% attrition rate) Of the 11 in the Skills-based group, 9 completed the intervention and their data was used in analysis (18% attrition). This high rate of attrition and small sample size means that it is difficult to draw meaningful conclusions from the data and limits the generalisability of the findings. In addition the differential rate of attrition in the two arms suggests that the mindfulness intervention was not as acceptable to participants as the skills based intervention.

Although the authors did use a matched comparison pairs design this was solely based upon their individual scores on the PSI-SF and the groups differed significantly on their pre treatment PSI-SF and General Health Questionnaire scores. The authors failed to identify or control for any potential confounding factors beyond individual scores of the PSI-SF. They used t-tests to analyse their data however, due to the small sample size these results may not be replicated in future studies. Another short coming of this study is that the authors failed to report validity and reliability scores for the measures used.

Singh et al. (2006) conducted a small case series looking at the impact of a 12 week parental mindfulness course on the behaviour of children with a diagnosis of autism and parental functioning. Their results suggest that mindful parenting decreases children's aggressive, non-compliant and self injurious behaviour and increases mother's satisfaction with their parenting skills and interactions with their children. Although these results appear to be promising, caution is needed as this is a small study with only 3 participants. The participants involved appear to be self-selecting and there is no information provided regarding the representativeness of the population or how they were selected. This limits the generalisability of the study. There was no control/comparison group used and potential confounding factors were not considered. No standardised measures were used calling into question the reliability of the procedures used. All data collected was based upon parental self report and the measures used were subjective. No statistical data was reported.

Weiss et al. (2013) conducted a study which examined the effectiveness of a social skills group for children with high functioning autism and their parents. Their results

suggest that children's overall social skills and general self worth increased and that parental psychological acceptance and empowerment also increased.

The study participants were families who could afford to pay for treatment and therefore the sample is unlikely to be representative of the general population. In addition to this limitation, of the 50 families who attended the group, only 35 families made up the final sample. This high level of parental incompleteness of data limits the generalisability of the findings. The authors do not provide information regarding how many families were approached to participate. There is no control/comparison group used in the study therefore it is not possible to identify what caused the reported change following intervention.

Another limitation of this study is that the authors failed to control for confounding factors which may have influenced the results. The measures used within the study were of acceptable validity and reliability although the sample size was limited and no power calculation was reported. The authors used appropriate statistical analyses. This study also relied upon parental self report therefore the reported changes may have been effected by parents' expectations of success as they were aware that their child participated in the intervention.

Discussion

The results of this review suggest that psychological acceptance and mindfulness may be concepts related to well-being in parents of children with developmental disabilities. The studies reviewed suggest that when parents of children with developmental disabilities report higher level levels of acceptance and mindfulness they also report lower levels of psychological distress. The intervention studies reviewed also suggest that acceptance and mindfulness based interventions may be effective at improving parental psychological well-being.

Although the overall results of this review suggest promising evidence for the development of acceptance and mindfulness based practice with parents of children with developmental disabilities it is important to the note that the quality of the studies reviewed was generally poor and further research is required to clearly establish this relationship.

Findings from cross-sectional studies - Acceptance

Of the six cross-sectional studies reviewed, four of them specifically measured parental psychological acceptance. Three of the four studies (McDonald *et al* 2010; Jones *et al* (In press); Weiss *et al* 2012) used the Acceptance and Action Questionnaire – Intellectual Disability Parent version (AAQ-ID; McDonald *et al*, 2010) and this has been shown to yield high internal consistency. Lloyd and Hastings (2008) used an adapted version of the original Acceptance and Action Questionnaire (Hayes *et al*. 2004). All authors found that parents who were more psychologically accepting had better outcomes in relation to mental health. These studies used a

variety of measures to assess parental mental health including measures of stress, anxiety and depression.

Taken together these results provide support for the hypothesis that parents who are more psychologically accepting have better mental health outcomes. However, the studies have numerous limitations as described previously. None of the studies reported a power calculation therefore they leave themselves open to Type II Error. All of the studies relied solely on parental self-report. One problem with self-report is that participants may only disclose information they consider to be acceptable and this may affect the outcome (Wylie 1961). Another difficulty with self-report is that even if participants are attempting to be as open and honest as possible they may lack the introspective ability to provide a 'true response'. Further, due to the cross-sectional design of the studies included, no causality can be implicated in the conclusions.

Findings from cross sectional studies – mindfulness

Three of the cross-sectional studies (McDonald & Hastings 2008; Beer *et al.* 2013, Jones *et al.* In press) looked specifically at mindful parenting. Their results suggest that being more mindful in regard to parenting can have a positive effect on parental mental health and parent child relationships. Beer *et al.* (2013) also found that higher levels of child behavioural problems were associated with lower levels of mindful parenting. Contrary to expectations they found that mindful parenting did not mediate the relationship between child behavioural problems and parental distress. They also found no relationship between mindful parenting and anxiety symptoms.

Jones et al (In press) however found that general mindfulness and mindful parenting did have significant mediation effects for maternal anxiety, depression and stress.

Two of the studies (MacDonald & Hastings 2008; Beer *et al* 2013) used Duncan's (2007) Inter-Personal Mindfulness in Parenting Scale. Jones et al (In Press) used two different measures of mindfulness, The Five Facets Mindfulness Questionnaire (FFMQ; Baer *et al* 2006) and a measure specifically designed for their study, The Bangor Mindful Parenting Scale (BMPS). The variety of measures used between the studies could perhaps account for the differences in results. The studies suffered from low response rate which hampers the generalisability of their results and questions the general acceptability of mindfulness intervention in this population. Again, they relied upon parental self report and the difficulties with this have been described previously.

Findings from Intervention Studies – Acceptance

Two of the six intervention studies (Blackledge & Hayes 2006; Weiss *et al* 2013) looked at the effect a group intervention (ACT group; Social Skills Group) had on parental psychological acceptance and well-being. Both studies found that participation in the group intervention resulted in parents reporting to be more psychologically accepting of their child and resulted in parents reporting improvements on measures of depression, well-being and empowerment. However these studies were considered to be poor in quality therefore their results need to be interpreted with caution. Perhaps most significantly, neither study used a control or comparison group and therefore they were unable to account for variables such as expectation of success, social support or time. They also failed to consider or

control for confounding factors such as parental employment status, family income or child behavioural difficulties.

Findings from Intervention Studies – Mindfulness

Four of the six intervention studies focused on mindfulness. However, three of these studies (Ferraioli & Harris 2012; Sign *et al.* 2006; Sign *et al.* 2007;) were low in quality. Their results do little to help us answer the research question. In contrast, one of the strongest studies in this review was conducted by Neece (2013). His results suggest that teaching parents Mindfulness Based Stress Reduction (MBSR) can significantly reduce their stress levels and depressive symptoms and result in them reporting greater life satisfaction. One of the strengths of this study is that they used a control group, however their sample size was small and they relied solely upon parental self report.

In general the reviewed studies provided support for the usefulness of concepts such as acceptance and mindfulness in helping to support parents of children with developmental disabilities. In cross sectional studies, acceptance appears to be a construct that is linked to important outcomes, suggesting its potential as a treatment target. Supporting this hypothesis, intervention studies that are designed to influence mindfulness and acceptance do show benefits in terms of parental well-being. Poor study quality means that further research needs to be conducted in this area, and the current review suggests that this should be a worthwhile endeavor. Future research should attempt to address some of the limitations that have been discussed in this review.

Limitations of this review

As the inclusion criteria limited the review to peer reviewed journal articles and to English language studies it therefore excluded unpublished studies that were potentially relevant. Another potential limitation is the quality criteria used. Although the criteria helped the review to be more systematic it may have also led to potential misunderstandings. For example, if a paper used appropriate statistical analysis but failed to use appropriate measures then the scores can be misleading as they may suggest adequate study quality when in fact the use of inappropriate measures may negate the result. Also, the cross-sectional studies were of questionnaire based design. They tended to score low in terms of external validity as their response rate was typically low, however response rates are typically low for studies of questionnaire based design and this is not necessarily reflected in their score.

Future research considerations

In order to provide significant evidence for the effectiveness of acceptance and mindfulness interventions in parents of children with developmental disabilities future research should focus on controlled intervention studies of a pre, post and follow up design. Researchers should consider the wide range of confounding factors which may influence parental psychological well-being (economic status, social support, level of child's disability, family composition etc) and attempt to control for these. Large studies which report adequate statistical power are also required.

The majority of the studies considered in the review use measures of parental mental health measures (stress, anxiety and depression) as indicators of parental well-being. However, recent reports (Scottish Executive 2000; Mencap 2010; The

Scottish Government 2013) have suggested that Quality of Life (QOL) is a key area of importance in developmental disabilities research and it should be used as a standard measure of functioning by services working with families who have developmental disabilities (Lin *et al.* 2009). Future researchers may wish to conduct studies examining whether acceptance and mindfulness interventions can improve the quality of life of families who have children with developmental disabilities.

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Journal Article

Psychological Acceptance and Family Quality of Life in Families of Children with
Intellectual Disabilities.

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Disabilities.

Abstract

Background Enhancing the quality of life of families with children with intellectual disabilities is a key target for government and professionals. Ascertaining the psychological factors that may influence family quality of life is important as this may identify the psychological process that could be amenable to change. This present study explores parental psychological acceptance and emotional adjustment and examines whether these variables account for some of the variance in family quality of life.

Method One-hundred and twenty-nine parents of children with intellectual disabilities participated in a questionnaire based study. Participants completed measures of family quality of life, psychological acceptance, emotional adjustment, mental well-being and impact of the child.

Results Parental psychological acceptance was positively associated with family quality of life and was found to account for around 1.9 per cent of its variance. Parental emotional adjustment was also positively associated with family quality of life, however, when parental psychological acceptance was added to the regression model emotional adjustment was no longer a statistically significant variable.

Conclusions The results of this study suggest that parental psychological acceptance may explain some of the variance in family quality of life. Further research is needed to ascertain whether interventions that improve parents' psychological acceptance also improve family quality of life.

Introduction

The birth of a child is often a joyful event surrounded by hope, excitement and expectation. However, raising a child can be challenging for many parents and it has been widely agreed that parents of children with intellectual disabilities experience more challenges and demands than parents of typically developing children (Glidden *et al.* 2006; Lloyd & Hastings 2009). In addition to the increased practical demands of caring for a child with intellectual disabilities (e.g. finding specialist care providers; gaining access to scarce resources) parents of children with intellectual disabilities have the additional psychological task of coming to terms with their child's condition and limitations. It is therefore not surprising that these parents can experience higher levels of stress, depression and anxiety than parents of typically developing children, and many researchers suggest that this is a result of the additional adjustments these parents have to make due to having a child with an intellectual disability (Lloyd & Hastings 2008; Neece 2003; Sloper & Turner 1993). Research has linked parental distress to a variety of negative outcomes for children with intellectual disabilities including higher rates of child psychopathology and anti-social behaviour, a failure to engage with professionals and decisions to have their child cared for out with the family home (Emerson *et al.* 2006).

However, not all parents who have children with intellectual disabilities report distress or problems with adjustment (Lloyd & Hastings 2009). Consideration of the factors that influence this process may be helpful when thinking about how best to provide support for those parents who do experience distress.

Parental adjustment or adaptation is a multifaceted process which involves a variety of factors including child, family, environmental and psychological variables. Much research has focused on the impact the child, family and environmental factors have on parental psychological well-being but it is only fairly recently that psychological processes themselves have become the focus of research (Lloyd & Hastings 2009). Recently there have been a number of studies which have found that psychological processes (e.g. parental self-efficacy, locus of control, self-esteem, acceptance) have an effect on parental wellbeing in the context of having a child with a disability (Lloyd & Hastings 2009; Hastings & Brown 2002; McDonald *et al.* 2010).

Loss & Grief for Parents of Children with Intellectual Disabilities

Authors considering the complexities involved in the adaptation of parents who have a child with an intellectual disability have proposed the literature on loss and grief as a useful framework in which to consider this process (Bruce *et al.* 1994). It has been suggested that after a child receives a diagnosis of intellectual disability, parents can experience an emotional reaction similar to that experienced after the death of a loved one (Bruce *et al.* 1994). Barnett *et al.* (2003) provide a list of common parental reactions to the news of child disability:

- Feeling devastated, overwhelmed and traumatized by the news
- Shock, denial, numbness and disbelief

- Feelings of crisis and confusion
- Sense of loss for the 'hoped for child'
- Grief reaction
- Expectations and hope for the future are challenged or destroyed
- Feelings of guilt, responsibility and shame
- Strong anger directed towards professionals involved
- Wondering whether things would be better if the child dies
- Decreased self-esteem and efficacy as parents
- Marital and other family relationships become severely strained
- Family routines are disrupted

Barnett *et al.* (2003) define adaptation as '*an ongoing process whereby parents are able to sensitively read and respond to their child's signals in a manner conducive of healthy development*' (p 184) and suggest that through working with "*parental perceptions, thoughts and emotional reactions*" effective adaptation can be achieved. They suggest that parents have to grieve for the child they expected and develop a representation based on their child's actual abilities in order to be able to respond sensitively to them. This grieving process is complicated by the fact that physically their child is not lost '*Instead, these parents are grieving for their hoped for child – the child they were expecting never arrived*' (Barnett *et al.* 2003, p187). Worthington (1989) suggests that there are three aspects of this grief: the loss of the 'perfect child', the real challenges the child brings and the impact this child has on the family. Contrary to intuition and Kubler-Ross's (1969) stages of grief model, time since diagnosis does not seem to have an impact on parent's passage through the process of 'grief' (Bruce *et al.* 1994; Barnett *et al.* 1999). Barnett *et al.* (2003) identify a

number of challenges in adapting to having a child with intellectual disabilities including the re-experiencing of grief at each developmental transition, preoccupation with guilt, anger and blame, unknown implications of the diagnosis and parental avoidance, denial and suppression of negative feelings.

There are a number of ways in which grief models are a less useful lens through which to view this area. Firstly, viewing parents as being in a continuous state of mourning for the loss of their 'perfect' child is unlikely to be helpful as it presents parents as being the relatively passive victim of their child's disability (Feinberg & Vacca 2000). Secondly, the grief model taken from the death and bereavement literature (Kubler-Ross, 1969) suggests a stage like process which results in 'completion'. For parents living with a child with intellectual disabilities this fails to consider the impact the developing child may continue to have on parental psychological adaptation. As their child develops and the discrepancies in ability between them and a typically developing child become more apparent they may actively revisit adjustment tasks, particularly at transitions in the child's life (e.g. attending school, leaving home). Parental adaptation is considered to be an active and ongoing process throughout the child's life (Sloper & Turner 1993) rather than something that is 'completed'.

Psychological Acceptance

Parents of children with intellectual disabilities can feel responsible, blamed, guilty and ashamed of their child's condition (Blackledge & Hayes 2006). The idea of avoidance, denial and suppression of negative feelings having an impact on parental adaptation is similar to the concept of psychological acceptance. Psychological acceptance can be defined as "the voluntary adoption of an intentionally open, receptive, flexible, and non judgemental posture with respect to moment-to-moment experience" (Hayes *et al.* 2012, p. 272). Within the context of parents of children with intellectual disabilities and autism this seems to be a useful concept, considering the daily burden of care, the 'finality' of diagnoses such as autism and Intellectual Disability, and the scarce support resources. The thoughts and feelings experienced by these parents are not inaccurate or exaggerated, given the challenges they face.

Acceptance approaches are part of the family of cognitive behavioural approaches, but rather than attempting to alter cognitions and emotions they aim to encourage parents to cultivate a willingness to experience uncomfortable thoughts and emotions and maintain contact with the present moment; "being able to accept the challenges that one is unable to change may be as helpful or more helpful than advocating for services" (Weiss *et al.* 2012). As Blackledge and Hayes (2006) suggest, Acceptance and Commitment Therapy (ACT) *"seems particularly applicable to the psychological situation faced by these parents"* (Blackledge & Hayes 2006, p2) as it focuses on the acceptance of the unpleasant thoughts and feelings these parents may have rather than trying to alter these thoughts and emotions as other therapies may suggest. Recent research (Lloyd & Hastings 2008;

McDonald *et al.* 2010) has shown that psychological acceptance can have an impact upon parental wellbeing and adjustment.

Quality of Life

Most previous studies in this area use measures of stress, depression and anxiety to ascertain a level of parental functioning. However, quality of life has become a key area of importance and focus in intellectual disability research (Summers *et al.* 2005, Cramm & Nieboer, 2012) and improving Quality of Life is an implicit aim of many service providers (Brown *et al.* 2003). According to the World Health Organisation, Quality of Life can be defined as *“individuals’ perception of their position in life in the context of the culture and values system in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment”* (World Health Organisation 1997). Over the past 30 years the concept of Quality of Life has evolved and become an important construct that guides practice and provides a framework for measuring personal outcomes (Verdugo *et al.* 2012). When considering the lives of adults and children with intellectual disabilities ensuring that they *“experience the same human rights and a life of quality as any other member of society”* (Verdugo *et al.* 2012 p 1037) is paramount. Many government documents have targets relating to the improvement of Quality of Life for people with intellectual disabilities and their families (Scottish Executive 2000; The Scottish Government 2013) and it has been suggested that measures of Quality of Life should be part of a standard set of measures used to assess people’s wellbeing to *“identify aspects of*

life, physical, psychological or social, that could be improved with intervention” (Lin et al. 2009, p1449).

Family Quality of Life

A further development of this research has been to consider Family Quality of Life. Family Quality of Life looks beyond individual Quality of Life and encompasses all family members' needs. Family Quality of Life is achieved when all family members needs are met, when they enjoy spending time together as a family and when they are able to take part in activities that they enjoy and find meaningful (Davis & Gavidia-Payne 2009; Park *et al.* 2003).

Family Systems Theory and Family Centered Practice

Contemporary understandings of child development acknowledge that children do not develop in isolation and that the functioning of the family can greatly impact upon the child's development and functioning (Dempsey *et al.* 2009). These views have foundations in family systems theory which highlights that family interactions are extremely important and that each member of the family is impacted by other family members (Davis & GavidiaPayne 2009). Following on from this, it has been suggested that when families are functioning well they are more able to facilitate and promote healthy child development. Therefore, improving factors that influence family quality of life may have an indirect positive effect of the individuals within the family system. Intervention programs '*can indirectly influence children by focusing on other aspects of the family system and enhancing*

Family Quality of Life” (Davis & GavidiaPayne 2009 p154). This family centered approach has now become an integral aspect of service provision and is considered fundamental to services which provide support to children with intellectual disabilities and their families (Freedman & Bower 2000; Law *et al.* 2005). Family centered approaches recognise that parents are at the heart of their children’s care and development and that they should be considered to be ‘experts’ regarding their child’s requirements and capabilities.

Some of the factors which are known to influence parent’s adjustment to having a child with an intellectual disability have been considered above. A recent systematic review by Walsh *et al* (unpublished) has found some evidence that acceptance and mindfulness interventions for parents of children with intellectual disabilities can positively influence parental well-being. This study aims to bring together two strands of current research, family quality of life and parental psychological acceptance, and examine the extent to which parental emotional adaptation and parental psychological acceptance impacts upon family quality of life. A measure of parental resources and stress is included as parental stress has been found to have a negative impact upon parent’s quality of life (Huang *et al.* 2014). Parental mental well-being will also be measured as this has been shown to have an impact on children’s quality of life (Wiley & Renk 2007). We hope this research will further extend the evidence base to provide support for the development of interventions that help support parents acceptance of their child's disability and ultimately improve their family’s quality of life.

The aim of this paper is to test an empirical model that statistically predicts family quality of life. In particular we are interested in the relative predictive contribution of parental psychological acceptance, emotional adaptation, mental wellbeing, and impact / burden of the child. Hierarchical linear regression was used to test this model.

Hypotheses

1. Parental psychological acceptance will contribute significantly to the variance found in family quality of life out come when all relevant child and parent demographic variables are controlled for.
2. Parental emotional adaptation will contribute significantly to the variance found in family quality of life when all relevant child and parent demographic variables are controlled for

Additional Hypotheses

1. Parental mental well being will contribute significantly to the variance found in family quality of life when all relevant child and parent demographic variables are controlled for.
2. Parents burden and stress will contribute significantly to the variance found in family quality of life when all relevant child and parent demographic variables are controlled for.

Method

Power Considerations

In order to detect moderate strength relationships between four predictor variables and one dependent variable, using multiple regression, at an alpha of .05, with 80% power a minimum sample of 84 participants was needed (Cohen 1992). The justification for detecting a medium effect size is based on previous research using similar measures. In these unpublished studies across diverse samples (Tansey *et al.* 2010; Ferenbach *et al.* 2011; Ferreira *et al.* 2011) correlations between measures of acceptance and quality of life were at or above 0.5, which is considered to be a large effect size (Cohen 1992).

Measures

A demographic questionnaire designed for the study was used to collect this data. This information is reported in the participants section. Five additional standardized measures were used in the study.

Impact/Burden . The Friedrich Short-Form of the Questionnaire on Resources and Stress (QRS-F: Friedrich *et al.* 1983) was used to measure the impact of having a child with intellectual disability had on family functioning. This measure is a 52-item tool which assesses parental perceptions about parent and family problems, pessimism, child characteristics and physical incapacity. Examples of items include, 'Other family members do without things because of N,' and 'N doesn't communicate with others of his/her age

group'. Responses are given in a True/False format. Higher scores are indicative of greater distress within a family. Scott et al. (1989) found internal consistency of the scale to be high with a Cronbach's alpha of .92. Internal consistency for the current sample was high ($\alpha = 0.88$)

Parental emotional adaptation. Emotional adaptation to having a child with an intellectual disability was measured using the Judson Scale (Judson & Burden 1980). This scale was designed to measure how parents adapt emotionally to having a child with a disability and considers this adaptation in relation to four aspects; the parents own feelings; their interactions with their disabled child; their perceptions of the child's progress and their relationships with professionals. Respondents answer on a 7 point numerical rating scale, anchored on each end with opposing statements such as 'My child and I have lots of fun together' versus 'My child and I don't have any fun together'. Items are rated 1-7 with a total score range of 22-154. This scale has been used to measure adaptation in several studies of families with children with intellectual disabilities (Mobarak et al. 1999). Honey et al. (2005) have found internal consistency of this measure to be high, with a Cronbach's alpha of 0.88. Internal consistency for the current sample was high ($\alpha = 0.85$)

Parental psychological acceptance. Parental psychological acceptance was measured using an adapted version of the 'Acceptance and Action Questionnaire – II' (AAQ II)(Bond et al. 2011). The original AAQ II was adapted and reworded by McDonald et al. (2009) to make it

apply explicitly to children with intellectual disabilities and is called the AAQ-Intellectual Disability Parent Version. This is an eight item scale and looks specifically at parental acceptance of the feelings and thoughts related to parenting a child with intellectual disabilities. Examples of items include 'It's ok if I remember some of the difficult times I've had parenting my child with intellectual disability' and 'Emotions relating to my child with intellectual disability cause problems in my life'. Higher scores on this item indicate that individuals are less psychologically accepting. This adapted version has been used in several studies and high levels of internal consistency have been found (Cronbach's alpha coefficients between 0.80 -0.92)(McDonald *et al.* 2009; Weiss *et al.* 2013; Jones *et al.* in press). Internal consistency for the current sample was high ($\alpha = 0.87$)

Parental mental well-being. In order to assess parental mental well-being the Warwick-Edinburgh Mental Well-Being Scale (WEMWBS: Tennant *et al.* 2007) was used. This scale contains 14 positively phrased items looking at the positive aspects of mental well-being. Examples of items include 'I've been feeling useful' and 'I've been thinking clearly'. Responses are given in the form of a 5 point Likert scale ranging from 'none of the time' to 'all of the time'. Possible scores range between 14 to 70 with higher scores indicating greater levels of mental well-being. The WEMWBS has shown high levels of internal consistency (Cronbach's alpha 0.91) and high test-retest reliability (0.83)(Tennant *et al.* 2007). Internal consistency for the current sample was high ($\alpha = 0.93$)

Family quality of life. The Beach Centre Family Quality of Life Scale (FQoL: Hoffman *et al.* 2006) was used to measure quality of life for families who have a child with intellectual disabilities. It is a 25 item scale and respondents rate items on a scale of 1 to 5 in terms of their satisfaction, ranging from 1= Very Dissatisfied to 5 = Very Satisfied. Examples of items include 'My family member with a disability has support to make friends' and 'Adults in the family teach the children to make good decisions'. Higher scores indicate greater family quality of life. The scale has an overall Cronbach's alpha of 0.88 (Hoffman *et al.* 2006) Internal consistency for the current sample was adequate ($\alpha = 0.80$)

Procedure

Two child intellectual disability services in East Central Scotland agreed to participate in the study. The study was reviewed and approved by the South East Scotland Research Ethics Committee 01 (Reference - 11/SS/0068) and the Research and Development offices in both Health Boards. The study was also reviewed by the University of Edinburgh School of Health in Social Science Research Governance Procedure. The research was conducted in accordance with the code of conduct for research with human participants as described by the British Psychological Society, including informed consent, right to refuse / withdraw, confidentiality. Potential participants were identified from referral databases held by the services participating. Recruitment to the study opened in March 2012 and closed in July 2012. 412 families were sent an information sheet and questionnaire pack. To conform with anonymity requirements, the whole initial sample was sent a reminder letter and a

second questionnaire pack, thanking those who had responded and asking those who wished to participate but had not yet responded to do so. A total of 129 parents returned completed questionnaires resulting in a 31% response rate.

Participants

Participants were 129 parents of children diagnosed with an intellectual disability. The main inclusion criteria were that the potential participants were the parents of a child aged 18 or younger who had an intellectual disability and lived at home with them. Participants were also required to be able to understand written English in order to complete the questionnaires. Parents were identified as their child had been referred to one of two services supporting the psychological needs of children and young people with intellectual disabilities. No information was gathered regarding the children's level of intellectual function however in order to receive support from the specialist services involved, children needed to meet criteria for an intellectual disability (IQ below 70 and significant impairment in adaptive behaviours). Demographic information was available for 120 participants. The parents ranged in age from 25-62 years (mean 43.82 years; SD = 6.96 years). The majority of participants were female (N=109, 90.8%) and the majority of families had more than one child; range 1-6 children (mean 2.36 SD 1.13). The children with intellectual disabilities were aged between 1 year and 18 years (mean 11.53 SD 4.26). 70.8% of the sample had children with an additional diagnosis. Just under half of the children (49.2%) had a diagnosis of autism, 5% had a diagnosis of Attention Deficit Hyperactivity Disorder and 16.6% had other diagnoses including Down's Syndrome, Smith Megenis Syndrome and Prader-Willi

Syndrome. 71% of the sample were married, 8.3% were living with a partner, 5% were in a relationship, 7.5% were divorced or separated, 5% single and 2.5% were widowed.

Results

Data Analyses Plan

Preliminary analyses were conducted to check for missing data and normality. Missing data for the standardised variables were few (less than 2.5%) therefore mean imputation was conducted. Nine participants failed to return any demographic information and list-wise deletion was used for this missing data.

Pearson correlations and t-tests were conducted to examine any relationships between demographic variables and family quality of life. Hierarchical linear regression was used with family quality of life as the dependent variable. The independent variables were entered into the regression model using the 'enter' method, in order with the best known predictors of quality of life being entered first.

Correlational Analysis

Pearson correlations were used to examine relationships between all demographic information, child variables and parental outcome measures, and t-tests were used to determine if there were significant differences between subgroups (e.g. sex) of the sample in terms of the independent and dependent variables. This step was used to identify control variables for the regression models, however no significant associations or subgroup differences were found therefore they were not included as covariates in the regression model.

Table 1 Shows correlation coefficients among all the independent variables. Overall, the results indicate that there are important relationships between the independent variables as well as with the outcome measure of family quality of life. Although these measures are significantly associated, the magnitude of correlations is not so high as to suggest problems of multicollinearity (Field 2009, p223).

Table 1. Correlations between variables

| | Mental Wellbeing | Emotional Adaptation | Psychological Acceptance | Impact/Burden |
|-----------------------------|---------------------|-------------------------|-----------------------------|---------------|
| Family QoL | 0.630* | 0.628* | -0.602* | -0.578* |
| Mental Wellbeing | - | 0.685* | -0.608* | -0.537* |
| Emotional Adaptation | | - | -0.692* | -0.618* |
| Psychological Acceptance | | | - | 0.569* |

Pearson's R, *p < 0.01

Regression Analysis

The main statistical analyses employed hierarchical linear regression with family quality of life as the dependent variable. In order to check that the residuals were normally distributed histograms and normal probability plots were conducted for each regression. A normal distribution of residuals was seen for all regression analyses. Predictors were selected on past research with known predictors being entered into the model first. The first step entered was Impact of the Child of family functioning (Impact/Burden). In the second step Parental Mental Well Being (Mental Wellbeing) was added as a predictor. The

third step added is Parental Emotional Adaptation (Emotional Adaptation) and the final step entered Parental Psychological Acceptance (Psychological Acceptance) as a predictor.

Table 2 shows the contribution each independent variable had on the outcome measure of Family Quality of Life at each step in the model. Overall, the final step indicates that this is a successful model with just over 50 percent of the variance in Family Quality of Life being explained by the independent variables. This model suggests that acceptance is a significant predictor of family quality of life, even after substantial proportions of the variance of quality of life are accounted for by the other predictors, making a conservative test for the acceptance construct. Of note, when acceptance is entered into the model at the final step, the contribution of adaptation is no longer significant. This suggests that acceptance is a stronger predictor of Family Quality of Life than adaptation.

Table 2. Hierarchical Linear Regression Analysis

| <i>Model /Step</i> | <i>Variable</i> | β | <i>t</i> | <i>p</i> | R^2 | Adj R^2 | $R^{2Change}$ | <i>F(df)</i> | <i>p</i> |
|--------------------|---------------------------------|---------|----------|----------|-------|-----------|---------------|--------------|----------|
| 1. | <i>Impact/Burden</i> | -0.578 | -7.98 | <0.001 | 0.334 | 0.329 | 0.334** | 63.706 | <0.001 |
| 2. | <i>Impact/Burden</i> | -0.337 | -4.412 | <0.001 | 0.478 | 0.469 | 0.143** | 57.575 | <0.001 |
| | <i>Mental wellbeing</i> | 0.449 | 5.88 | <0.001 | | | | | |
| 3. | <i>Impact/Burden</i> | -0.247 | -3.032 | 0.003 | 0.506 | 0.494 | 0.029** | 42.68 | <0.001 |
| | <i>Mental Wellbeing</i> | 0.323 | 3.675 | <0.001 | | | | | |
| | <i>Emotional Adaptation</i> | 0.254 | 2.687 | 0.008 | | | | | |
| 4. | <i>Impact/Burden</i> | -0.211 | -2.567 | <0.011 | 0.523 | 0.508 | 0.017* | 33.988 | <0.001 |
| | <i>Mental Wellbeing</i> | 0.283 | 3.180 | 0.002 | | | | | |
| | <i>Emotional Adaptation</i> | 0.172 | 1.699 | 0.092 | | | | | |
| | <i>Psychological Acceptance</i> | -0.191 | -2.100 | 0.038 | | | | | |

** p < 0.01; * p<0.05

Discussion

The results of the current study suggest that parental psychological acceptance is a significant factor in family quality of life. Parents who reported being more accepting of the negative thoughts and feelings associated with raising a child with intellectual disabilities also reported higher levels of family quality of life. The regression model indicates that, even when parental mental well-being, parental resources and stress and parental adaptation are included in the model, the result remains significant and parental psychological acceptance accounts for around 1.9% of the variance in family quality of life. Another finding of note is that when acceptance is added in to the regression model, adaptation is no longer a significant predictor of variance in family quality of life. This result suggests that psychological acceptance has more influence on family quality of life than emotional adaptation.

This study provides a novel approach to examining the impact psychological acceptance has upon family functioning as it focuses on family quality of life as the outcome measure rather than distress experienced by parents. Previous research has shown that parents who are more psychologically accepting report fewer symptoms of anxiety, depression and stress (Lloyd & Hasting 2008; McDonald *et al.* 2009; Weiss *et al.* 2013). This research adds to this body of work and highlights that parental acceptance is a construct that is also linked to the important outcome of family quality of life. In an early study, Blackledge and Hayes (2006) conducted a study looking at the effectiveness of an Acceptance and Commitment training (ACT) group in helping parents of children with autism better adjust to the difficulties of raising their child. They found that general distress and depression levels decreased

significantly following participation in the group and that these decreases were maintained at three month follow up. Although this study provides some evidence that acceptance is a construct that is amenable to change in parents of children with intellectual disabilities, further research in this area is needed as this was a small uncontrolled study. Although previous research in this area has focused on stress, depression and/or burden as outcome measure there are limitations to this approach. Constructs of stress, depression and burden tend to have negative associations and in measuring them negative experiences are assumed to be present. This position may fail to capture the potential positive or neutral aspects of having a child with a disability on the family (Summers *et al.* 2005). The negative connotations associated with these concepts may also have an effect on the responses parents provide which may be critical in studies relying solely on parental self-report measures. The impact a child's intellectual disability has on family functioning is complex and multifaceted. Focusing on stress, depression and burden as indicators of parental adaptation focuses solely on their psychosocial adjustment and fails to consider the multi-dimensional aspects of family life that may play a role in family well-being.

In recent years those working in the area of intellectual disabilities have agreed that supporting families and providing services using family centred approaches are vital concepts which should be at the heart of disability policy and practice (Turnbull *et al.* 2006). Although family quality of life is an area of research which is only just emerging (Pozo *et al.* 2014) there is extensive agreement that this new construct is important for increasing a family's ability to adapt to and cope with raising a child with intellectual disabilities (Gine *et al.* 2013). The Beach Centre Family Quality of Life Scale used in this study was designed to

encapsulate the complex and multifaceted factors that impact upon family quality of life. Summers *et al.* (2005) aimed to bring together three aspects which were viewed as impacting upon the adjustment of families with children with intellectual disabilities to produce one overall measure of family quality of life; Stress, depression and burden; Family Functioning in terms of their communication, flexibility, role performance and coping processes; and Eco-cultural adaptation – the practical adjustments the family have had to make in terms of their daily routine for living, working and socialising (Summers *et al.* 2005). The current research is the first of its kind to examine the impact psychological acceptance has upon all of these processes as is encapsulated by the family quality of life measure.

It is essential to consider the limitations of this study and interpret the results with caution. Firstly, although the response rate was relatively high for a study of questionnaire based design, only 31% of people invited to participate responded. This means that the sample that responded may not be fully representative of the general population of parents of children with intellectual disabilities. Also, there was a much higher proportion of mothers who responded with over 90% of the sample being female. While this may be a reflection of the cultural norms (with mothers tending to be the main care provider for their children) it means that our findings may not be equally generalisable to of fathers of children with intellectual disabilities. Replication of these findings in other samples of parents, particularly men, is necessary. Secondly, as parents provided details of their own functioning, reporting biases may have influenced results. One problem with self-report is that participants may only disclose information they consider to be acceptable and this may

affect the outcome (Wylie 1961). Also, even if participants are attempting to be as open and honest as possible they may lack the introspective ability to provide a 'true response'. Future research would benefit from multiple reports from varying sources.

A further limitation of this study is that it did not control for all potential confounding variables. Although many potential confounders were considered, family income was not included in these. Previous research in this area has shown that socio-economic disadvantage can account for a significant amount of poorer well-being among mothers of children with intellectual disabilities (Emerson *et al.* 2006) suggesting that this is a variable which should be controlled for in future research. A final limitation of this study is that it is cross-sectional in design therefore no claims of causality can be made. The statistical relationships observed do provide a first step in highlighting acceptance as a *potential* treatment target that could impact on improved family functioning. Further intervention studies will be required to test this hypothesis, though the current study suggests that such investigations are justified.

Implications for future research

Future research is needed to replicate the findings of this study while additionally controlling for the potential confounding factor of socio-economic disadvantage. It would also be of benefit if future research in this area included intervention studies. These would

provide opportunities to ascertain whether acceptance based interventions are able to improve reported levels of family quality of life.

To the author's knowledge this is the first study of its kind to use family quality of life as an outcome measure in a study of parental psychological acceptance. Future research into acceptance of parents of children with intellectual disabilities should consider the use of a family quality of life outcome measures as they encompass many dimensions of family well-being not only psychological functioning.

Implications for clinical practice

The present study has implications for clinical practice in the field of intellectual disabilities. Our finding that psychological acceptance accounts for almost two percent of the variance in family quality of life, after controlling for established predictors provides support for further investigation in to whether acceptance based interventions can help to improve family quality of life in families who have a child with intellectual disabilities. If acceptance based interventions can be shown to improve family quality of life then it may be useful to make 'acceptance' training available to families who have a child with intellectual disabilities. The present study suggests than acceptance is a significant factor in family quality of life and therefore it is important that all professionals working with families who have a child with intellectual disabilities are aware of the psychological processes that may be affecting family functioning and well-being.

This research indicates that family quality of life is influenced by a variety of factors including parental mental well being, emotional adaptation and psychological acceptance. These are concepts that examine the psychological adjustment/well-being of parents of children with intellectual disabilities and this study suggests that they impact significantly upon family quality of life. In order to help support families with children with intellectual disabilities the services working with them need to consider the psychological well-being of parents and the impact this has on family functioning as a whole. Although more traditional 'functional analysis' and 'behavioural' therapy will always have a role in psychological services working with children with intellectual disabilities, this research indicates that parental psychological functioning is an important concept for clinicians to consider. Interventions focused on improving parental psychological functioning/well-being may have the potential to improve family quality of life and ultimately improve the lives of children with intellectual disabilities.

As is highlighted in this paper, family quality of life is an emerging concept in the field of intellectual disabilities. Service providers should consider the family as a 'whole' entity rather than solely working with the individual with the disability. In order to assess and measure the effectiveness of interventions provided for families a measure of family quality of life could be used as part of a standard set of measures at pre, post and follow up points in order to identify current difficulties and to assess whether intervention has been effective. This focus on family functioning may highlight to families the importance of the system their child lives in and the impact each member of the system/family has upon

overall functioning and well-being. The completion of a family quality of life measure has the potential to serve as a useful therapeutic task in itself.

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Please note that any manuscripts uploaded as Word 2007 (.docx) will be automatically rejected. Please save any .docx files as .doc before uploading.

4.2 Blinded Review

All articles submitted to the journal are assessed by at least two anonymous reviewers with expertise in that field. The Editors reserve the right to edit any contribution to ensure that it conforms with the requirements of the journal.

5. MANUSCRIPT TYPES ACCEPTED

Original Articles, Review Articles, Brief Reports, Book Reviews and *Letters to the Editor* are accepted. *Theoretical Papers* are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

6. MANUSCRIPT FORMAT AND STRUCTURE

6.1 Format

Language: The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found at http://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

6.2 Structure

All manuscripts submitted to the *Journal of Applied Research in Intellectual Disabilities* should include:

Cover Page: A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.

Running Title: A short title of not more than fifty characters, including

spaces, should be provided.

Keywords: Up to six key words to aid indexing should also be provided.

Main Text: All papers should be divided into a structured abstract (150 words) and the main text with appropriate sub headings. A structured abstract should be given at the beginning of each article, incorporating the following headings: Background, Materials and Methods, Results, Conclusions. These should outline the questions investigated, the design, essential findings and main conclusions of the study. The text should then proceed through sections of Introduction, Materials and Methods, Results and Discussion, and finally Tables. Figures should be submitted as a separate file.

Style: Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:

- Include all figure legends, and tables with their legends if available.
- Do not use the carriage return (enter) at the end of lines within a paragraph.
- Turn the hyphenation option off.
- In the cover email, specify any special characters used to represent non-keyboard characters.
- Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).
- Use a tab, not spaces, to separate data points in tables.
- If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

6.3 References

The reference list should be in alphabetic order thus:

- Emerson E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities*. Cambridge University Press, Cambridge.
- McGill P. & Toogood A. (1993) Organising community placements. In: *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services* (Eds E. Emerson, P. McGill & J. Mansell), pp. 232-259. Chapman and Hall, London.
- Qureshi H. & Alborz A. (1992) Epidemiology of challenging behaviour. *Mental Handicap Research* 5, 130-145

Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown *et al.* 1977). Authors are responsible for the accuracy of their references.

We recommend the use of a tool such as EndNote or Reference Manager for reference management and formatting.

EndNote reference styles can be searched for here:

<http://www.endnote.com/support/enstyles.asp>

Reference Manager reference styles can be searched for here:

<http://www.refman.com/support/rmstyles.asp>

The Editor and Publisher recommend that citation of online published papers and other material should be done via a DOI (digital object identifier), which all reputable online published material should have - see www.doi.org/ for more information. If an author cites anything which does not have a DOI they run the risk of the cited material not being traceable.

6.4 Tables, Figures and Figure Legends

Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption.

Figures should be referred to in the text as Figures using Arabic numbers, e.g. Fig.1, Fig.2 etc, in order of appearance. Figures should be clearly labelled with the name of the first author, and the appropriate number. Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained. In the full-text online edition of the journal, figure legends may be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.

Preparation of Electronic Figures for Publication

Although low quality images are adequate for review purposes, print publication requires high quality images to prevent the final product being blurred or fuzzy. Submit EPS (line art) or TIFF (halftone/photographs) files only. MS PowerPoint and Word Graphics are unsuitable for printed pictures. Do not use pixel-oriented programmes. Scans (TIFF only) should have a resolution of at least 300 dpi (halftone) or 600 to 1200 dpi (line drawings) in relation to the reproduction size. Please submit the data for figures in black

and white or submit a Colour Work Agreement Form. EPS files should be saved with fonts embedded (and with a TIFF preview if possible).

Further information can be obtained at Wiley-Blackwell's guidelines for figures: <http://authorservices.wiley.com/bauthor/illustration.asp>.

Check your electronic artwork before submitting it:
<http://authorservices.wiley.com/bauthor/eachecklist.asp>.

Permissions: If all or parts of previously published illustrations are used, permission must be obtained from the copyright holder concerned. It is the author's responsibility to obtain these in writing and provide copies to the Publisher.

Colour Charges: It is the policy of the *Journal of Applied Research in Intellectual Disabilities* for authors to pay the full cost for the reproduction of their colour artwork

http://www.blackwellpublishing.com/pdf/SN_Sub2000_X_CoW.pdf

7. AFTER ACCEPTANCE

Upon acceptance of a paper for publication, the manuscript will be forwarded to the Production Editor who is responsible for the production of the journal.

7.1 Proof Corrections

The corresponding author will receive an e-mail alert containing a link to a website. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF file from this site.

Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from the following website:

www.adobe.com/products/acrobat/readstep2.html

This will enable the file to be opened, read on screen, and printed out in order for any corrections to be added. Further instructions will be sent with the proof. Proofs will be posted if no e-mail address is available; in your absence, please arrange for a colleague to access your e-mail to retrieve the proofs.

Proofs must be returned to the Production Editor within 3 days of receipt.

As changes to proofs are costly, we ask that you only correct typesetting errors. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately. Other than in exceptional circumstances, all illustrations are retained by the Publisher. Please note that the author is responsible for all statements made in their work, including changes made by the copy editor.

7.2 Early View (Publication Prior to Print)

The *Journal of Applied Research in Intellectual Disabilities* is covered by Wiley-Blackwell's Early View service. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have a volume, issue or page number, so Early View articles cannot be cited in the traditional way. They are therefore given a DOI (digital object identifier) which allows the article to be cited and tracked before it is allocated to an issue. After print publication, the DOI remains valid and can continue to be used to cite and access the article.

7.3 Author Services

Online production tracking is available for your article through Wiley-Blackwell's Author Services. Author Services enables authors to track their article - once it has been accepted - through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The author will receive an e-mail with a unique link that enables them to register and have their article automatically added to the system. Please ensure that a complete e-mail address is provided when submitting the manuscript. Visit <http://authorservices.wiley.com/bauthor/> for more details on online production tracking and for a wealth of resources include FAQs and tips on article preparation, submission and more.

For more substantial information on the services provided for authors, please see Wiley-Blackwell's Author Services.

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Please note that unless specifically requested, Wiley-Blackwell will dispose of all hardcopy or electronic material submitted two issues after publication. If you require the return of any material submitted, please inform the editorial office or Production Editor as soon as possible.

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Free access to the final PDF offprint of the article will be available via Author Services only. Additional paper offprints may be ordered online. Please click on the following link, fill in the necessary details and ensure that you type information in all of the required fields:
<http://offprint.cosprinters.com/blackwell>

If you have queries about offprints please email offprint@cosprinters.com

Appendix 2 Critical Appraisal Checklist – Adapted from NICE guidelines

| | |
|--|--|
| <u>Section 1: Population</u> | |
| <p>1.1 Is the eligible population or area representative of the source population or area? (are important groups under-represented?, e.g., are participants with co-morbidity excluded? is this described well?)</p> <p>0) Poor or not described 1) Some information on the above or if some groups are under-represented 2) Comprehensive description of the above and no/very little under-representations of groups</p> | |
| <p>1.2 Do the selected participants or areas represent the eligible population or area? (Was methods of selection well described? What percentage of selected individuals agreed to participate?)</p> <p>0) Very limited information on the above or if there was a significantly small amount of eligible population who agreed to participate 1) Some information on the above available and a reasonable amount of the eligible population agreed to participate 2) Comprehensive description of inclusion/exclusion criteria, the methods of selection are well described and a significant number of eligible population agreed to participate</p> | |
| <u>Section 2: Method of selection of exposure (or comparison) group</u> | |
| <p>2.1 Was there a control/comparison group?</p> <p>0) No, or no information given on this 1) yes, but unclear how well matched 2) Yes and well matched</p> | |

| | |
|---|--|
| | |
| <p>2.2 Was the selection of explanatory variables based on a sound theoretical basis? (How sound was the theoretical basis for selecting the explanatory variables?)</p> <p>0) Very limited information on the above or no sound theoretical basis 1) Some information on the above available and some evidence of a sound theoretical basis 2) Comprehensive description of the sound theoretical basis</p> | |
| <p>2.3 How well were likely confounding factors identified and controlled? (Were there likely to be other confounding factors not considered or appropriately adjusted for?)</p> <p>0) Very limited information on the above or no consideration of potential confounding factors 1) Some information on the above available and some acknowledgement of potential confounding factors 2) Comprehensive description of potential confounding factors</p> | |
| Section 3: Outcomes | |
| <p>3. Were the outcome measures and procedures reliable? (information regarding validity/reliability?)</p> <p>0) Low validity/reliability or non-standardised measures 1) Acceptable validity and reliability 2) High validity and reliability</p> | |

| | |
|--|--|
| | |
| <u>Section 4: Analyses</u> | |
| 4.1 Sample size and power (Power calculation undertaken and reported using reasonable effect size estimation and sufficient numbers of participants in groups) 0) not reported or low, 1) acceptable 2) good | |
| 4.2 Appropriate analysis for outcome measures is used and confidence intervals, effect sizes and p-values are reported where appropriate 0) Poor method of statistical analyses used, not well described confidence intervals, effects sizes and p-values not reported for any analysis 1) Appropriate quantitative analyses used but less fully described and reporting of confidence intervals, effect sizes and p-values is less clear 2) Appropriate quantitative analyses used. Confidence intervals, effect sizes and p-values reported for every analysis | |
| <u>Section 5: Summary</u> | |
| 5.1 Are the study results internally valid (i.e. unbiased)? (How well did the study minimise sources of bias (i.e. adjusting for potential confounders)? Were there significant flaws in the study design?) 0) Given if there were no measure taken to minimise sources of bias and if there were significant flaws in the study design 1) Given if some attempt was made to minimise sources of bias 2) Given if specific and focused attempts were made to minimise sources of bias | |

| | |
|---|--|
| | |
| <p>5.2 Are the findings generalisable to the source population (i.e. externally valid)? (Are there sufficient details given about the study to determine if the findings are generalisable to the source population? Consider: participants, interventions and comparisons, outcomes, resource and policy implications.)</p> <p>0) Given if generalisability is extremely limited or if no information is given about this</p> <p>1) Given if there is some information given about this and if the results are somewhat generalisable</p> <p>2) Given if comprehensive account of information is given to determine generalisability and if the results are significantly generalisable</p> | |

Number of Participant –

Location –

Study Design –

Age-

Measures Used -

Appendix 3 Ethical Approval REC Committee

South East Scotland Research Ethics Committee 01

Waverley Gate
2 - 4 Waterloo Place
Edinburgh
EH1 3EG

:

29 November 2011

Mrs Allison Walsh

NHS Fife

Psychology Department

Lynebank Hospital

Halbeath Road

Dunfermline

KY11 4UW

Dear Mrs Walsh,

Study title: The relationship between acceptance and family quality of life in parents of children with intellectual disabilities.

REC reference: 11/SS/0068

Thank you for your letter of 28 November 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Version Date

Investigator CV

Participant Information Sheet 6.0 28 November 2011

Protocol 3 31 August 2011

Questionnaire: Booklet

A SHORT-FORM OF THE QUESTIONNAIRE ON

RESOURCES AND STRESS (QRS-F)

REC application 18 October 2011

Response to Request for Further Information 28 November 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

11/SS/0068 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely,

Dr Janet Andrews

Chair

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments [if final opinion was confirmed was given at a meeting]

Copy to: Dr David Gillanders

Dr Amanda Wood, NHS Fife

South East Scotland Research Ethics Committee 01

Attendance at Sub-Committee of the REC meeting

Committee Members:

Name Profession Present Notes

Dr Janet Andrews Associate Specialist Yes

Mr Lindsay Murray Health & Safety Manager Yes

Also in attendance:

Name Position (or reason for attending)

Mr Walter Hunter Committee Coordinator

Appendix 4 Caldicott Approval Fife



Counter-signature by Operational Division/Primary Care Caldicott Guardian

Name:

Job Title:

Signature: Una A. Clark Date: 22/12/11

Please forward to:

Una Hill
Data Protection & Caldicott Coordinator
NHS Fife
Information Services Department
Lynebank Hospital
Dunfermline KY11 8JH

I authorise access to the data as noted above:

Signature: DR EDWARD COYLE Date: 23/12/11
Caldicott Guardian for NHS Fife

ADMIN USE ONLY

| | |
|--|-----------------|
| Applicant's Name & Project Title <u>WALSH</u> <u>Acceptance of Parents of Children w intellectual disabilities</u> | |
| Date application received UH | <u>11/11</u> |
| Date sent for approval to CG OD/PC | |
| Date received by CG OD/PC | |
| Date sent to Board CG for formal approval | <u>22/12/11</u> |
| Date received by Board CG | <u>25/12/11</u> |
| Date returned to UH | |
| Date received by UH | |
| Date applicant informed | |

V5 -Nov 2010

University Hospitals Division

Queen's Medical Research Institute
47 Little France Crescent, Edinburgh, EH16 4TJ

CPP/SS/approval

1 March 2012

Mrs Allison Walsh
Psychology Department
Lynebank Hospital
Dunfermline
KY11 4UW



Research & Development
Room E1.12
Tel: 0131 242 3330
Fax: 0131 242 3343

Email: R&DOffice@luht.scot.nhs.uk

Director: Professor David E Newby

Dear Mrs Walsh,

Lothian R&D Project No: 2011/P/PSY/24

Title of Research: The relationship between acceptance and family quality of life in parents of children with intellectual disabilities

REC No: 11/SS/0068

CTA No: N/A

Eudract: N/A

PIS: Version 6 dated 28 November 2011

Protocol No: Version 3 dated 31 August 2011

I am pleased to inform you that this study has been approved for NHS Lothian and you may proceed with your research, subject to the conditions below. This letter provides Site Specific approval for NHS Lothian.

We note that this project includes researchers who will require a Clinical Research Access letter from NHS Lothian. The individuals concerned (Allison Walsh) should contact our offices with a view to applying for the necessary documentation. Please note all final paperwork will have to be signed and returned to our R&D offices before a researcher can commence work on the project.

Please note that the NHS Lothian R&D Office must be informed if there are any changes to the study such as amendments to the protocol, recruitment, funding, personnel or resource input required of NHS Lothian. This includes any changes made subsequent to management approval and prior to favourable opinion from the REC.

Substantial amendments to the protocol will require approval from the ethics committee which approved your study and the MHRA where applicable.

Please inform this office when recruitment has closed and when the study has been completed.

I wish you every success with your study.

Yours sincerely

A handwritten signature in black ink, appearing to read 'C Phillips'.

Dr Christine P Phillips
Deputy R&D Director

cc Paul Dearie, QA Manager
Pamela Shand, NRS

Appendix 6 Management Approval



Mrs Allison Walsh
Psychology Dept
Lynebank Hospital
Halbeath Road
DUNFERMLINE
KY11 4UW

Medical Director, Primary Care
Room 313
Hayfield House
Hayfield Road
KIRKCALDY
Fife KY2 5AH
Tel 01592 643355
www.show.scot.nhs.uk/fpct

Date 27 January 2012
Our Ref 11-083 NRS11/GH40
11/SS/0068
Enquiries to Aileen Yell
Tel No 01383 565110
Email aileenyell@nhs.net

Dear Mrs Walsh

Project Title: Acceptance in parents of children with intellectual disabilities

Thank you for your application to carry out the above project. Your project documentation (detailed below) has been reviewed for resource and financial implications for NHS Fife and I am happy to inform you that NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

| Document | Version | Date |
|---|---------|------------------|
| Protocol | 3 | 31 August 2011 |
| IRAS R&D Form | 3.2 | 6 October 2011 |
| IRAS SSI Form | 3.2 | 2 November 2011 |
| REC provisional favourable opinion letter | | 4 November 2011 |
| REC favourable opinion letter (revised) | | 29 November 2011 |
| Various documents referred to in REC letter | | |
| NRS-CC Certificate of Compliance | | 18 January 2012 |

The terms of the approval state that you are the Principal Investigator authorised to undertake this study within NHS Fife. Separate Site Specific Review is not required in this case.

The sponsors for this study are University of Edinburgh.

Details of our participation in studies will be included in annual returns we are expected to complete as part of our agreement with the Chief Scientist Office. Regular reports of the study require to be submitted. Your first report should be submitted to Dr A Wood, R&D Manager, R&D Resource Centre, Lynebank Hospital, Halbeath Rd, Dunfermline, KY11 4UW (Amanda.wood3@nhs.net) in 12 months time and subsequently at yearly intervals until the work is completed. A Lay Summary will also be required upon completion of the project.

In addition, approval is granted subject to the following conditions:-

All research activity must comply with the standards detailed in the Research Governance Framework for Health & Community Care (<http://www.cso.scot.nhs.uk/publications/resgov/resgov.htm>), health & safety regulations, data protection principles, other appropriate statutory legislation and in accordance with Good Clinical Practice (GCP).



Any amendments which may subsequently be made to the study should also be notified to Aileen Yell, Research Governance Officer (aileen.yell@nhs.net) , as well as the appropriate regulatory authorities. Notification should also be given of any new research team members post approval and/or any changes to the status of the project.

This organisation is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. This is achieved by random audit of research. You will be required to assist with and provide information in regard to monitoring and study outcomes (including providing recruitment figures to the R&D office as and when required).

As custodian of the information collated during this research project you are responsible for ensuring the security of all personal information collected in line with NHS Scotland IT Security Policies, until the destruction of this data.

Permission is only granted for the activities for which a favourable opinion has been given by the REC (and which have been authorised by the MHRA where appropriate).

The research sponsor or the Chief Investigator or local Principal Investigator at a research site may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety. The R&D office (aileen.yell@nhs.net) should be notified that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action. The R&D office should be notified within the same time frame of notifying the REC and any other regulatory bodies.

I would like to wish you every success with your study and look forward to receiving a summary of the findings for dissemination once the project is complete.

Yours sincerely



DR STELLA CLARK
Medical Director, Primary Care
NHS Fife

*Cc : Aileen Yell, Research Governance Officer, NHS Fife, Lynebank Hospital, Dunfermline
NHS Research Scotland C, R&D Office, Foresterhill House Annex, Foresterhil, Aberdeen AB25 2ZB*



Acceptance and Family Quality of Life in parents of children with intellectual disabilities.

Participant Information Sheet

I would like to invite you to take part in a research study looking at the experiences of parents who have a child with intellectual disabilities. This study is part of my psychology training for a Doctorate in Clinical Psychology with the University of Edinburgh. Before you decide if you want to take part, you need to understand why the research is being done and what it would involve for you. Please take time to read this information carefully. Talk to others about the research if you wish.

What is the purpose of the research?

Some research has suggested that parents who have a child with intellectual disabilities (also known as learning disabilities) experience more stress and anxiety than other parents. However, there is other evidence that suggests that being a parent of a child with intellectual disabilities can be a positive and beneficial experience. I am interested in finding out more about the psychological processes that may impact upon parents' experiences and possibly have an effect upon family quality of life.

Why have I been invited to take part?

You have been invited to participate in this research as you are the parent of a child who has been referred to either the Child Learning Disability service in NHS Fife or the NHS Lothian Child and Adolescent Mental Health Service Learning Disability & Autism team. We are asking parents who have a child with intellectual disabilities to participate in the research. We will be contacting approximately 450 families across NHS Lothian and NHS Fife. Your contact details have been obtained with permission from NHS Lothian CAMHS LD & Autism team or the NHS Fife Child Learning Disability Service with permission from those responsible for data protection in the NHS and will be kept confidential.

Do I have to take part?

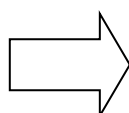
No, it is up to you to decide. Please keep this information sheet and take as long as you need to decide whether or not to take part. It is often recommended that you

spend at least 24 hours between reading the information sheet and taking part. Even if you have started to fill in the questionnaire, you can stop taking part at any time or choose not to return it. While you may take as long as you like to decide if you would like to take part in the study it would be helpful if the questionnaires could be returned within a four week period.

To help ensure the questionnaire is anonymous, there is no consent form. Implied consent is used, so if you complete and return the questionnaire, you are consenting for the information you provide to be used in this research project, as described in this information sheet. Since the questionnaire is anonymous, once you have returned the questionnaire, you will not be able to withdraw your questionnaire from the study. Your decision whether or not to participate will not affect the care you or your child receive.

What will I have to do if I take part?

If you take part, there is a questionnaire booklet to complete; the process involved is explained below in the boxes. Participation is voluntary and no payment is given.



Please complete the questions in the questionnaire booklet. This will take about 25-30 minutes. By completing and returning the questionnaire, you are consenting for the information you provide to be used in this research project. If you prefer to complete the questionnaire over the phone or face-to-face, please contact me to arrange that.

Please then seal the questionnaire in the envelope provided and post back (no stamp is required).

If you wish to be informed of the results directly, please phone or email me, to provide your details (I will not be able to link your contact details with any returned questionnaires).

Is there anything I should be worried about if I take part?

If you are thinking about your experiences of being a parent of a child with intellectual disabilities this may become upsetting for you. Especially if you are feeling particularly distressed or feel low at the moment. If you think answering the questions might upset you then you may not wish to take part. If anything upsets you or if you feel you need more support, please contact the lead researcher for advice. Also, parents can often feel stressed and sometimes have difficulty coping. If you would like more support please contact the lead researcher or alternatively go to www.moodcafe.co.uk where details of support organisations can be found.

What happens at the end of the research?

Once you have completed the questionnaire and sealed it in the stamped-addressed envelope provided, you can return it in the post – no stamp is required. The questionnaire will be kept in a locked NHS cupboard. The data from the questionnaires will be entered on to secure NHS computers for analysis and anonymised data will be shared with the University of Edinburgh project supervisor and will be stored there. All data will be destroyed from the date of publication in a peer reviewed journal. If you have provided your contact details, you will be posted a copy of the results. The findings will also be written up for publication and may be presented at conferences.

Will it be kept confidential?

Yes – all information collected will be kept strictly confidential, in accordance with NHS Fife policies. The questionnaire is completely anonymous, and I will not know the identity of anyone who has returned a questionnaire.

Who is organising and paying for the research?

It is being organised by the NHS and the University of Edinburgh. I am doing this research as part of my normal paid job, which is funded by NHS Fife.

Who has checked that the study is ok to go ahead?

The South of Scotland Research Ethics Committee on Medical Research Ethics, which has responsibility for scrutinising all proposals for medical research on humans in Fife and Lothian, has examined the proposal and has raised no objections from the point of view of medical ethics. This research has also been approved by the University of Edinburgh research committee.

Thank you for reading this – please ask me (Allison Walsh, Lead Researcher) any questions you have:

email: allisonwalsh1@nhs.net or phone: 01383 565 210

If you would like to talk to somebody independent of the project for advice on taking part you can contact Tara Graham, Research & Service Development Psychologist on 01334 696 336 or email taragraham@nhs.net

If you wish to make a complaint about the conduct of the research please contact:
Dr Heather Wilkinson, Research Director, School of Health in Social Science
h.wilkinson@ed.ac.uk



15th June 2012

Reminder Letter – Acceptance and Family Quality of Life in
parents of children with intellectual disabilities.

Dear parent/carer,

You may remember that I wrote to you at the end of March 2012 asking you to consider participating in my research project. I would like to thank those who have completed the questionnaires for their participation and ask those who would like to participate but have not yet done so to complete the enclosed questionnaires at their earliest convenience. I have included the participant information sheet again for your information. If you have decided not to participate in the project I would like to thank you for your time and ask you to ignore this reminder letter. If you have any queries about this research you are welcome to contact me via the details below.

Yours sincerely,

Allison Walsh
Lead Researcher
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email: allisonwalsh1@nhs.net or phone: 01383 565 210

Appendix 9 Skewness and Kurtosis Values

| | Skewness | | Kurtosis | |
|--|-----------|------------|-----------|------------|
| | Statistic | Std. Error | Statistic | Std. Error |
| Family Quality of Life | -.255 | .214 | -.251 | .425 |
| Warwick Edinburgh Mental Well-being Scale | -.153 | .214 | -.029 | .425 |
| Perental Adaption to the Child | -.278 | .217 | -.468 | .430 |
| Acceptance (ACT) in Parents of Child with LD | .189 | .217 | -.530 | .430 |
| Questionnaire on resources and stress | .085 | .218 | -.737 | .433 |